

BioTrust Community Values Advisory Board Minutes  
Monday, February 3, 2014  
East Lansing, MI

**CVAB Members Present**

*Voting Members*

☐ Linda Burghardt  
☒ Karen Calhoun  
☒ Denise Chrysler  
☒ Susan Dendrinis  
☒ Rosalyn Beene Harris

☒ Tedra Jackson  
☒ Joyce Kornbluh  
☒ Neil MacVicar  
☐ \*Mary Lou Mason  
☒ Ella Greene-Moton

☒ \*\*Tressa Orthmeyer  
☒ Stephen Rapundalo  
☐ Tina Reynolds  
☒ Thomas Rich  
☐ Rita Walters

**CVAB Designees**

☒ \*John Roy Castillo  
☐ \*\*Peggy Rush

*Community Attendees:* E. Hill De Loney, Yvonne Lewis, Ann Mongoven, Ariel Brovont

*MDCH Staff:* Carrie Langbo

**1. Welcome and Introductions... Tedra Jackson**

- T. Jackson welcomed board members and guests. Introductions were made. Quorum established.

**2. Review of 9.9.13 Minutes**

- Minutes approved (motion by N. MacVicar). Posted on BioTrust website ([www.michigan.gov/biotrust](http://www.michigan.gov/biotrust)).

**3. MDCH Updates**

- MDCH IRB/SAB:** Please refer to Blood Spot Research link on BioTrust website for study summaries (BioTrust Blood Spot Research Report updated 1/2014 and the 2<sup>nd</sup> edition of the Community Research Report). Discussion ensued regarding Community Research Report. Suggestion made to replace this report with lay version of scientific abstracts in the Blood Spot Research Report. Ann Mongoven stated her deliberative jurors would prefer a lay version of each abstract in the Blood Spot Research Report, and stated the number of times the reports are viewed on-line should not be used to gauge their value as many of her jurors simply want the knowledge of their accessibility.
  - Carrie will work on revising the Scientific Research Report while CVAB members discuss value of Community Research Report with their respective organizations and community members. Will re-visit during September meeting.
- BioTrust Coordinator:** (1) BioTrust annual report drafted for MDCH approval. Final report will be sent electronically to CVAB members and posted on BioTrust website. Future plan is to include BioTrust annual report as an addendum to the Newborn Screening Annual Report available on-line. (2) Consent Update: Audio recording of BioTrust consent brochure is on BioTrust website. Arabic and Spanish translation is available on-line, and professional printing will be completed once current stock of Arabic and Spanish booklets is depleted. ~80% of consent forms are being returned. From total screens, ~62% of samples have consent for BioTrust, 18% active refusal and 20% incomplete/not returned. Carrie continues quarterly contact with birthing hospitals submitting <80% completed forms. N. MacVicar offered Michigan Health and Hospital Association assistance. (3) Directive (store only or destroy) Requests: ~20 directives (preliminary) have been submitted since September's CVAB meeting. (4) 2014 MDCH Education/Engagement: Prioritize prenatal education with completion of prenatal care provider calls (~200 completed resulting in multiple orders for education material) and outreach to childbirth educators. Presentation January 17<sup>th</sup> to Michigan Childbirth Education Connection reaching childbirth educators in Lapeer, Livingston, Macomb, Monroe, Oakland, Sanilac, Washtenaw, and Wayne Counties. Facebook posts and Tweets will continue on MDCH social media platforms. MDCH Immunization Section granted permission to use college/university health clinic email list. Plan to contact clinics in October 2014

with BioTrust information packet (to be developed). D. Chrysler requested we consult APHL blood spot toolkit.

- i. CVAB ad-hoc work-group formed to assist Carrie with college/university health clinic outreach. Work-group: R. Beene Harris, T. Orthmeyer, T. Rich and K. Calhoun.
- CVAB Updates, Education and Outreach: (1) Minor revision made to CVAB Speaker/Exhibitor Form (attached) to record outreach and feedback for MDCH. (2) Ann Mongoven: Final draft of educational lecture tool, long and short version with scripts, will be sent to MDCH/CVAB for feedback. Two focus groups reviewing content were held since last CVAB meeting. Skepticism from participants regarding BioTrust education efforts between 2009 and present day was reported. Suggestion made to acknowledge skepticism but also inform on efforts made (>150 community/9 mass media events, etc.). Clarification provided on how new parents can confirm their consent decision- contact the NBS Program (contact info on all MDCH NBS/BioTrust education material). (3) Yvonne Lewis: Influenza Awareness week and community outreach since the fall has allowed education of >1,900 people. New parents recalled BioTrust consent process, and while some young people were skeptical all were very willing to converse about the BioTrust. 2014 events scheduled surrounding health heritage (May) and family health history month (November).

#### 4. 2014 Priorities

- (1) Michigan Association of Genetic Counselors: NBS/BioTrust flip card distributed at fall education conference with request for distribution after all counseling sessions. (2) Michigan Minority Health Coalition: upcoming event may utilize Spanish/Arabic BioTrust material. (3) MichBio: MDCH participated in October State Capitol event sponsored by MichBio and Michigan Neonatal Biobank featured in fall newsletter. Will determine feasibility for inclusion of a BioTrust article in a 2014 newsletter. (4) Member at Large, Karen Calhoun: Annual Community Engagement Program Spring Symposium can't feature BioTrust in break-out session but will explore abstract/poster option. (5) American Cancer Society: helping to establish in-roads with tribal health directors (6) Michigan Maternal and Child Health: Will follow-up regarding the Southeastern Michigan Association of Neonatal Nurses Conference, May 2<sup>nd</sup>. MDCH NBS/BioTrust exhibit already planned.

#### 5. Public Comments

- Ann Mongoven provided possible avenues for future outreach including: Michigander section of the Lansing State Journal, MSU Extension 4H youth conference/civic projects and sections devoted to newborn screening/research use of residual specimens in self-help literature for expectant parents. Requested update on RWJF research project regarding impact of BioTrust consent process. Carrie responded that project's principal investigator has been given MDCH data analysis and is drafting manuscript(s).

#### 6. Upcoming CVAB Meeting Agendas

- May 5, 2014: Will discuss 2015-16 membership and CVAB Chairperson